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Adherence to Treatment among Patients With End-Stage Renal Disease Undergoing Hemodialysis In Selected Centers In Nepal

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ABSTRACT

Background: Hemodialysis remains a commonly available treatment option for many patients with end-stage renal disease. In addition to regular hemodialysis, these patients require regular use of medicines, follow fluid restriction and dietary modification. Hence, adherence to treatment remains a major factor to improve survival and quality of life among these patients. Therefore, this study was carried out to identify the adherence to treatment among patients undergoing hemodialysis.

Methods: A cross-sectional study was conducted among 160 patients undergoing hemodialysis at three centers of Bagmati province of Nepal from July to December 2020. We used End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ) to record the adherence scores in different domains of treatment adherence. The scores were compared with different sociodemographic variables using nonparametric tests.

Results: Out of a total score of 1200, the overall obtained mean score was 1084.07±125.58. The percentage of the respondents adhering to dialysis, medicines, fluid, and diet was 91.9%, 76.3%, 48.9%, and 43.0% respectively. Male patients scored significantly higher score in the diet. And the married patients scored higher in adherence to fluid. Patients with middle socio-economic status scored significantly higher score in adherence to hemodialysis treatment.

Conclusions: More than half of the respondents were non adherent to fluid and diet. Periodic motivation by health care professional and dietary counseling by dietitians might be helpful to improve the adherence to treatment.

Keywords: Adherence; ESRD-AQ; hemodialysis; treatment.

INTRODUCTION

Chronic Kidney disease (CKD) and end-stage renal disease (ESRD) have been identified as the global public health burden.[1] Due to many reasons, like resource, constraints, and shortage of organ donation for transplantation, hemodialysis remains the preferred modality of treatment among ESRD patients in many parts of the world.[2-4] Proper management of ESRD requires strict patient adherence to treatment protocols to achieve favorable health outcomes and satisfactory quality of life.[5] Despite the provision of free dialysis service by the Government of Nepal since 2016, not all patients undergoing hemodialysis adhere to their treatment guidelines on regular basis.

There is a paucity of data on this important issue in Nepal.[6-8] Therefore, this cross-sectional study was conducted to assess the adherence to treatment among the patients with ESRD undergoing hemodialysis.

METHODS

This was a descriptive cross-sectional study conducted among patients with end-stage renal disease undergoing hemodialysis in three different hospitals of

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Bagmati province. Two of the centers were located in Kathmandu (one private teaching hospital and one semi-government) and one in the Chitwan district (Private teaching hospital).

Written permission and approval from the institutional review committees (IRC) of each of the institutions. Ethical approval was obtained from Nepal Health Research Council (Ref. No 566/2020 P. Verbal and written permission was obtained from the hospital administration and written consent was taken from the participants.

Treatment adherence was measured by using a structured self-administered questionnaire. Questionnaires were focused on the measurement of the behaviors that the patients with end-stage renal diseases (ESRD) followed during the last month (for hemodialysis) and the behaviors followed for medicines, fluid, and diet in the last week.

The independent variables included were age, sex, marital status, education level, socioeconomic status, and duration of hemodialysis treatment. Socioeconomic status was measured by Kuppuswamy's socioeconomic status scale and is classified as upper, middle (upper middle, lower middle), and lower classes (upper-lower, lower- lower).[9, 10]

The dialysis centers were selected as per the feasibility of the researchers. Altogether there were 238 patients undergoing hemodialysis in these centers. Recruitment of the participants was done as mentioned in Figure 1. The purposive sampling technique was used to enroll only literate patients to reduce the direct contact time as the study was conducted amidst the COVID-19 pandemic. Only the patients who were on maintenance hemodialysis for at least three months were included in the study. Those patients who had a vision problem denied participation, and were admitted to the intensive care unit (ICU) at the time of data collection were excluded from the study.

The treatment adherence was assessed by the standard end-stage renal disease adherence questionnaire (ESRD-AQ) developed by Kim Youngmee.[11] The tool was reliable valid and easy to administer. The tool was generated with the clinical experts (nephrologists and nephrology researchers- nurse practitioners), hemodialysis nurses, and renal dieticians. Content and construct validity were checked in the original tool and considered as a reliable and valid tool. Some of the questions from the original tool were removed as they were unrelated to the current study. The tool measured treatment adherence in four domains (hemodialysis attendance, medication use, fluid restrictions, and dietary recommendations). There were altogether six questionnaires, three related to hemodialysis attendance, and one on each related to medicines, diet and fluids. A modification was not required to the questions that measured the adherence behavior. The researcher, with the help of the biolinguistics translator, translated the questionnaire to Nepali, which was again back-translated to English.

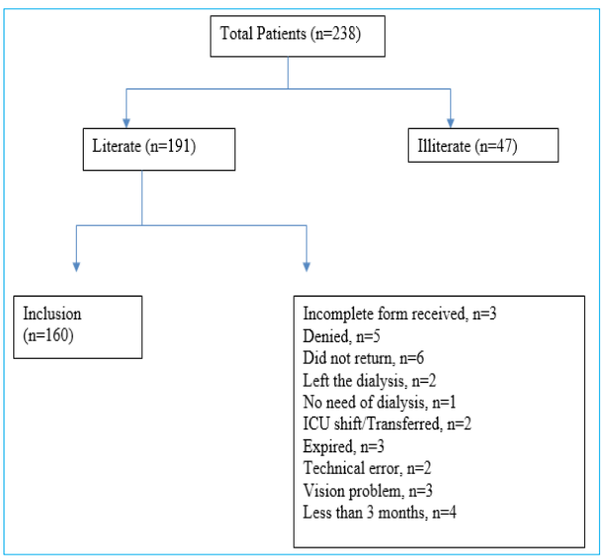

Figure 1. Recruitment of participant.

The scoring system was based on the degree of relevance to importance to clinical outcome. In the treatment adherence to hemodialysis, three questions were asked related to missed dialysis (score 0-300), episodes of shortening hemodialysis (0-200), and durations of shortening hemodialysis (0-100). The score was summated. Hence, for hemodialysis, the lowest score was 0 and, the highest was 600. Similarly, one question on each domain of medicines, fluid restriction, and dietary recommendations was asked. Respondents' were asked how often they missed medicines (none of the time -200, very seldom-150, about half of the time-100, most of the time-50, all of the time -0. Similarly asked questions on how often respondents' followed fluid restrictions recommendations (all of the time -200 to none of the time -0) and followed the dietary recommendations (all of the time -200 to none of the time-0. The overall score was summated and is ranged from 0 to 1200. The higher the score higher the adherence and vice versa.

There were altogether 24 questions and the average time taken to complete the form was from 10 to 15 minutes. The respondents were asked to fill the questionnaire form by themselves. The respondents were given choice to fill the form during waiting, after dialysis, or to take

it home as per their convenience.

Data were entered in excel version 10 and analyzed using IBM SPSS version 16. Descriptive statistics like percentage, mean, standard deviation, and median were presented in the table. To compare the distribution of the adherence score across different sociodemographic categories, the Mann-Whitney U test was used at a 95% confidence level (p-value <0.05).

RESULTS

Table 1. Sociodemographic variables (n = 160).

Variables	F	%
Age		
less than 42	79	49.4
more than or equals 42	81	50.6
Gender		
Male	108	67.5
Female	52	32.5
Maritial status		
Married	139	86.9
Single	15	9.4
Divorced	2	1.2
Missing	4	2.5
Education		
Up to 10 th grade	99	61.9
SLC pass	28	17.5
Higher secondary and above	30	18.7
Missing	3	1.9
Occupation		
Unemployed	104	65.0
Service/business/retired	37	23.1
Farmer	13	8.1
Student	4	2.5
Labor	2	1.3
Types of family		
Joint	142	88.7
Nuclear	15	9.4
Alone	3	1.9
Socio economic status		
Upper	1	0.6
Upper Middle	11	7.0
Lower Middle	44	27.5
Upper lower	64	40.0
Lower	6	3.8
Missing	34	21.1
Required hemodialysis in a week		
Once	3	1.9
Twice	100	62.5
Thrice	57	35.6

Table 2. Adherence to treatment among ESRD patients undergoing hemodialysis (n = 160).

Treatment Adherence	f(%)
Missed Dialysis in the last month	
None	149(93.1)
1-2 times	7(4.4)
3-4 times	4(2.5)
Episodes of shortening HD in the last month	
None	104(65.0)
1-2 times	17(10.6)
≥3 times	28(17.6)
Missing	11(6.8)
Duration of Shortening of HD in minutes	
Not applicable	104(65.0)
11-30 min	39(24.4)
≥ 31 min	17(10.6)
Frequencies of missed prescribed medicines in last week	
None of the time	120(75%)

Table 2. Adherence to treatment among ESRD patients undergoing hemodialysis (n = 160).	
Very seldom	32(20%)
About half to all of the time	7(4.4%)
Missing	1(0.6%)
Followed the fluid recommendations	
All of the time	78(48.8%)
Most of the time	49(30.6%)
About half to none of the time	29(18.1%)
Missing	4(2.5%)
Followed the diet recommendations	
All of the time	67(41.8%)
Most of the time	50(31.3%)
About half to none of the time	34(21.3%)
Missing	9(5.6%)

A total of 160 patients with ESRD undergoing hemodialysis participated in the study. The mean age of the respondents was 42 years. The majority of them (67.5%) were male. The majority of the participants (87%) were married and 61.9% had education less than or equal to 10th grade and 65% were unemployed. Regarding socioeconomic status, participants belonging to upper lower, lower-middle, and upper-middle class were 40%, 27.5%, and 7% respectively. The patients who required hemodialysis once, twice, and thrice a week were 1.9%, 62.5%, and 35.6% respectively. The majority (93.1) of the patient did not miss any dialysis treatment and 65% did not have any episodes of shortening of the dialysis treatment. Almost 75% of the participants reported they did not miss any prescribed medicines during the last month, whereas 4.3 % missed almost half to all of the time. Only Almost 48.8% mentioned that they followed the fluid recommendations in the last week and 41.9% followed the dietary recommendations all of the time. (Table 1 and Table 2).

The findings of the reasons for missing treatment that was assessed by open ended questionnaire is shown in table 4. These reasons were tallied as per original tool. All the reasons in missed hemodialysis shows non adherent behavior and were scored accordingly. The decisions for shortening of hemodialysis sessions were made by the health professionals as per the clinical scenario of the individual patients. So, the findings related to these parameters were given full score as adherent behavior during scoring. All other reasons as shown in table 3 on medicines and fluids were considered as non-adherent behavior. Seven patients mentioned that they forgot to take medicines and 36 patients stated feeling thirsty as the main reasons for not following fluid recommendations. Similarly, the major reasons for not following the dietary recommendations were that the participants could not control their desire to eat.

Table 3. Reasons of missed treatment(open ended).	
Reasons for missing dialysis	**No.**
No one to accompany to hospital	2
Missed bus/transportation	2
Because of some work	2
Because of headache/vomiting	1
Birthday of friends	1
Father Died	1
Reasons for shortening treatment	
Fistula Problems *	1
Difficulty in Breathing *	1
During covid as per doctor's prescription*	39
Missing Medicines	
Forget	7
Economic Condition	5
Medicines has not worked	1
When come for dialysis	5
Reasons for not following fluid restrictions	
Feeling thirst	36
Feeling difficulty	3
Sunny/ seasonal	4
Festivals	2
High dialysis flow	1
Eating out home	2
Passing urine	1
During medicine	1
Feeling 3 times treatment is enough	1
Reasons for not following dietary recommendation	
Cannot control	6
Desire to eat full	3
Different people cooking food at home	2
Goes out/guest at home	2
Not getting any advice	1
Feeling weakness	1
*Considered genuine reasons -received full score	

Table 4. Overall adherence behaviour (n = 135).

Treatment	Adherence (> mean value), f(%)	Non adherence (≤ mean value), f(%)	Mean±SD
Hemodialysis	124(91.9)	11(8.1)	585±54.93
Medications	103(76.3)	32(23.7)	184.44±32.59
Fluid	66(48.9)	69(51.1)	162.22±47.49
Diet	58(43.0)	77(57.0)	151.85±56.12
Overall	91(67.4)	44(32.6)	1084.07±125.58

Table 4 shows, altogether 67.4% of the participants adhere to overall treatment. The percentage of the patients with ESRD adhering to hemodialysis, medicines, fluid, and diet was 91.9%, 76.3%, 48.9%, and 43.0% respectively.

Table 5. Relationship between demographic variables and treatment adherence (n = 135).

Variables		Treatment				
	n=135	HD (600)	Medicine (200)	Fluid (200)	Diet (200)	Overall (1200)
Age		μ(σ)	μ±σ	μ±σ	μ±σ	μ±σ
<42 years	68	583.82(56.27)	183.08(35.20)	159.55(49.06)	152.94(56.57)	1079.41(127.32)
≥ 42 yrs	67	587.31(53.89)	185.82(29.90)	164.92(46.06)	150.74(56.06)	1088.80(124.56)
P		0.3830	0.7040	0.5200	0.7720	0.4810
Gender						
Male	98	581.12(63.21)	183.16(35.13)	159.69(51.60)	159.18(52.43)	1083.16(133.53)
Female	37	597.29(16.43)	187.83(24.73)	168.91(34.05)	132.43(61.48)	1086.48(103.17)
P		0.15	0.665	0.671	0.011	0.769
Maritial Status (n=131)						
Married	119	587.81(50.82)	185.71(29.21)	165.12(45.82)	155.46(53.19)	1094.11(114.27)
Unmarried	12	566.66(88.76)	170.83(58.22)	129.16(58.22)	120.83(72.16)	987.50(186.01)
P		0.212	0.386	0.013	0.071	0.011
Education (n=132)						
< SLC	85	582.35(62.06)	185.29(26.52)	165.88(39.49)	159.41(46.60)	1092.94(108.32)
≥ SLC	47	590.42(41.22)	182.97(42.06)	155.31(60.10)	138.29(67.73)	1067.02(153.67)
P		0.529	0.516	0.715	0.143	0.654
Socioeconomic Status (n=106)						
Low	54	574.07(75.69)	186.11(31.34)	163.88(44.94)	154.62(56.02)	1078.70(123.47)
Middle	52	598.07(13.86)	187.50(21.86)	166.34(46.14)	153.84(45.20)	1105.76(86.68)
P		0.03	0.693	0.694	0.524	0.38
Duration of HD treatment (n=132)						
< 3 years	79	589.87(34.32)	182.27(34.93)	163.92(49.31)	152.53(57.67)	1088.60(117.38)
≥ 3 years	53	578.30(76.90)	190.56(24.13)	157.54(45.35)	149.05(55.02)	1075.47(140.61)
P		0.896	0.099	0.227	0.586	0.977

p value considered significant at ≤ 0.05 at 95% Confidence Interval , p obtained from Man Whitney Test

Table 5 depicts the relationship between sociodemographic variables and adherence to each treatment and as a whole to adherent behaviour. The response regarding some of the treatment modalities were not completed by all of the participants. Therefore, the analysis related to adherence could be done only in 135 participants. Age did not influence the adherence behaviour. Males scored less in all the treatment modalities except in dietary adherence, where males had significantly higher scores than the female participants (159.18±52.43 versus 132.43

(61.48); p<0.01). Though, the participants who were married scored higher in all the treatment modalities, statistically significant result was obtained only in fluid restrictions and overall adherence behaviour. The scores in adherence to fluid restrictions among married and unmarried was 165.12±45.82 and 129.16±58.22 respectively that was significant at p<0.013. Similarly, the significant difference was found in terms of scores in overall adherence behaviour among the married and unmarried participants (1094.11±114.27 versus 987.50±186.01; p<0.01). The participants with middle socio-economic status had higher score in adherence to haemodialysis treatment in comparison to those with low socioeconomic status (598.07±13.86 versus 574.07±75.69; p<0.03). Education level and duration of hemodialysis treatment were not found to have an effect on adherence behavior.

DISCUSSION

Hemodialysis remains a major treatment option for many patients with ESRD. As the etiology of CKD is multifactorial, patients undergoing hemodialysis need to take multiple medications. Adherence to treatment remains a major factor for better outcomes among patients undergoing hemodialysis. However, multiple factors may play a role in non-adherence to treatment among patients with ESRD undergoing hemodialysis. This study done in three centers in the Bagmati province of Nepal has tried to explore the adherence to treatment among patients with end-stage renal disease undergoing hemodialysis.

A total of 160 patients who could read and write participated in the study. Males were predominant most of the participants were married and unemployed. Most of the patients undergoing dialysis were from upper lower socioeconomic backgrounds. Most of the patients required twice a week sessions. These demographic characteristics were similar to the previous studies conducted in different centers of the country in the past.[12, 13]

The majority of the participants in this study adhered to dialysis sessions, which is similar to the study conducted in the dialysis centers in the Kathmandu district.[12] More than ninety percent had not missed any dialysis session in the last month, which is higher than the study from Rwanda.[14] More than one-third of the participants mentioned that they were having a shortening of the dialysis sessions than usual. It could be due to the unexpectedly increased numbers of patients requiring hemodialysis with limited resources during the COVID-19 pandemic. As the decision of shortening the hemodialysis sessions was taken by the health professionals and the participants did not have any role in this regard, we assumed that all of the participants adhered to the duration of hemodialysis treatment. This is congruent with a study from Rwanda where about 5% of patients had shortening episodes and this shortened dialysis might be because of the machinery problems encountered during dialysis.[14] However the survey done by American Kidney Fund portrayed that 18-31% of ESRD patients canceled or end dialysis sessions early because of feeling sick or conflicting appointments.[15]

After dialysis, the second most adhered treatment modality was an intake of prescribed medicines regularly. About seventy-five percent of the participants took the prescribed medicines regularly in the last month, which is similar to the study from Nepal and the reports from the American Kidney Fund. [12,15] The reasons for missing medicines, as mentioned by the participants, were forgetfulness, financial constraints, and belief of sub-optimal response of medicines. Forgetting to take medicines was the main reason for missing or skipping medicines in the large survey done in the USA.[15] This finding would be helpful to encourage the dialysis nurses towards identifying these issues in day-to-day practice to remind the ESRD patients during each HD session to take the prescribed medicines.[16] Similarly, less than half of the patients adhered to fluid and dietary recommendations, which is similar to the findings from USA[15] but mismatched to the results from Nepal,[12, 13] which is probably because of the difference in the applied tool and scoring system. About sixty-seven percent of the patients in this study adhered to the overall dialysis treatment that is in congruence to the study conducted in Ruphandehi district of Nepal.[13]

Hemodialysis was the most adhered treatment. The score in the medication adherence is similar to the study conducted in Nepal and Palestine.[8, 17] Then the next highest score obtained in fluid restriction and dietary adherence respectively. The scores in fluid restriction and dietary adherence in this study are slightly higher than both the study as mentioned earlier. This may be because of the emergence of the COVID pandemic and the patients become more conscious about their comorbid state.

Based on the findings we can conclude that males scored significantly higher score in dietary adherence. Married patients obtained significantly higher scores in the dietary restrictions and in overall adherence treatment. This is similar to the study conducted in Nepal which showed that married scored higher in the overall adherence.[8] As the mean age of our respondents was forty-two and most were married, they might feel they have a parental obligation to live for their children and partner. Patients with middle socioeconomic status scored higher in the dialysis treatment and were statistically significant. This might be because of the other expenditure for the dialysis like coming to the dialysis center in an ambulance, use of medicines like erythropoietin and intravenous iron.

As the study was conducted during the COVID pandemic

time the findings may not be generalizable to the normal situation. As well the study had covered only those patients who can read and write by themselves so only strongly motivated patients might have participated in the study.

CONCLUSIONS

Though a majority of the patients adhered to hemodialysis and medication treatment, significant numbers of patients did not have better adherence to fluid and dietary restriction and overall treatment. Despite the provision of a free HD facility by the Government, about eight percent of the ESRD patients were non-adhered to hemodialysis and these patients need to be motivated to prioritize hemodialysis as the major treatment option. Therefore, optimal strategies need to be formulated and be implemented that would include regular dietary counseling by dieticians, reinforcing the support by the family members, and regular motivation from the dialysis nurses and the treating physicians/nephrologists.

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CONFLICT OF INTEREST

None.

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